A landmark study published in 1995 starkly highlighted successes and deficiencies in the care of dying patients in US hospitals. Known as the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), this investigation followed more than 9000 patients at 5 teaching institutions to determine the presence of advance directives, whether such directives were respected, and to what degree conscious patients dying in a hospital setting experienced significant pain. The initial study found that fewer than half of physicians knew when their patients preferred to avoid cardiopulmonary resuscitation (CPR), that half of the CPR orders were written within 2 days of death, that nearly 40% of patients spent at least 10 days in the intensive care unit (ICU) prior to death, and that 50% of conscious patients experienced moderate or severe pain prior to death, as reported by family members.

After a major study intervention in which discussions with patients, their families, and physicians were conducted by specially trained nursing personnel, and physicians were provided with periodic information regarding both short-term and 6-month prognosis and likelihood of CPR success, a follow-up study failed to confirm significant change in outcomes. The SUPPORT investigators highlighted the need for a significant change in clinical attitudes and practice if the way in which patients and families in America influence and experience dying is to change. A number of national organizations, including the Institute of Medicine, the American Academy of Family Physicians, the American Geriatric Society, and the American Medical Association have issued major position statements calling for more effective care and better training regarding patients and their families at the end of life.

This is the first part in a 2-part series on hospice and palliative care. Part 1 provides a historical context for the development of current hospice and palliative care services and reviews ways in which to identify the patient with a limited life expectancy. The Medicare hospice benefit is discussed, as well as certain pertinent ethical issues. Part 2 in the series, to be published in the January 2005 issue of Hospital Physician, discusses therapeutic interventions designed to maximize comfort for the patient with advanced progressive disease, whether formally enrolled in hospice or not. A hypothetical case illustrating these concepts is followed through both parts of the series.

**HISTORY OF THE HOSPICE MOVEMENT**

The modern field of palliative and hospice care emerged in the early 1960s. In the post–World War II period, a major shift in medical focus occurred, emphasizing the improved ability to diagnose and treat disease and disability and, thus, prolong life. Prior to that time, an acceptance of life-ending decline was more prominent; comforting the dying, primarily at home, was the dominant model of end-of-life care. Beginning in the 1940s, the technologic tools of disease modification grew exponentially. The 1960s and 1970s ushered in a period of aggressive cardiac and pulmonary care with the development of ICUs, ventilator support, and widespread use of dialysis. Hope of conquering cancer in the near future and growing faith in the powers of science swept death and care of the dying to the background.

The site of death increasingly shifted from home settings to acute care institutions. Between 1949 and 1980, the number of deaths in institutions increased from 50% to 74%. This transfer of location occurred even though approximately 80% of patients express a desire to die at home, if possible. These facts suggest that typical models of home care, institutional care, and family care of the dying were in significant discordance.

Against this background of changing care in the United States, hospice programs began developing in the mid-1960s. The early hospice programs were...
volunteer organizations with a particular focus on the psychosocial support of patients and families. Developed without external regulation, these programs provided profoundly important support to families and community caregivers, laying the groundwork for the subsequent development of hospice and palliative care models in the United States. In the last decade, palliative care consultation programs have developed, first in the university setting, and, increasingly, at the community hospital level.

GOALS OF PALLIATIVE AND HOSPICE CARE

**Palliative Care**

Palliative care is the provision of care with a primary focus on symptoms and their alleviation. It is often contrasted with curative or disease-modifying care, in which the primary focus is prolongation of life. It is increasingly recognized that care of patients should always represent a balance between these twin goals (Figure 1). A patient with early osteoarthritis will not be cured; instead, the thrust of treatment should consist of physical therapy to maximize function and administration of analgesic agents to relieve pain. Both of these interventions represent palliative care. Similarly, a patient with persistent renal cell carcinoma may initially be treated with chemotherapy and surgery in an attempt to cure the disease. Palliative care plans to address symptoms should be developed at the same time: nausea, vomiting, anorexia, fatigue and pain may all warrant attention. When no reasonable possibility of cure exists, care goals shift entirely to the palliation of symptoms through interventions designed to promote comfort and function.

In the United States, many clinicians have held to a model in which there is an abrupt transition from cure to comfort, usually when death is rapidly approaching. Such an abrupt model does not reflect the clinical reality.

Excellent palliative care should be part of every patient’s plan of care, whether it is a patient with newly diagnosed diabetes or a patient with end-stage dementia.

**Hospice Care**

Hospice is a particular model for the delivery of excellent palliative care. It is a well-planned and structured program and, with the Medicare hospice benefit, includes a financing mechanism. Hospice philosophy, although overlapping with palliative care in its attention to relief of symptoms, differs in its clear acknowledgment and acceptance of the inevitability of death. Hospice programs are for patients who have made the decision to accept comfort, not life prolongation, as the primary goal of care.

In the Medicare hospice model, patients are expected to have a likely prognosis of 6 months (or fewer) of life remaining (see Medicare Criteria for Admission to Hospice section, below). Treatment decisions are based not on the goal of preventing death but rather on the goal of providing comfort to both the patient and family as death-defining processes unfold. For example, a patient with end-stage pulmonary disease who develops respiratory failure would not be intubated, treated with aggressive corticosteroid and nebulizer therapy, or given fluids and antibiotic agents intravenously; rather, such a patient would be treated with medications to ease the terror of end-stage breathlessness (eg, opioids, benzodiazepines, anticholinergic agents [addressed in part 2 of this article series]) and with education—for the family as well—on the natural and inevitable progression of the respiratory failure. Similarly, a patient with end-stage dementia who becomes increasingly somnolent because of diminished oral intake generally would not be given fluids intravenously or nourishment via a feeding tube. Instead, the patient would be given mouth care, and the family would be educated about the burdens of artificial hydration/nutrition and the benefits of a usually gentle, progressive somnolence leading to coma. Simultaneously, there would be support for accepting the inevitable outcome. Hospice staff, including nurses, social workers, and chaplains, may increase the frequency of visits to help manage symptoms and to surround the family unit with reassurance and support.

For families electing care at home, hospice support can be essential. The social changes of the past 50 years have left few families with knowledge of how to care for someone declining and dying at home. Hospice provides a team of professionals to assist in that task.

Many patients faced with advanced progressive disease do not enroll in hospice programs. In 2002,
885,000 patients were enrolled in hospice care. Although this figure has increased steadily each year, the number of people who die in hospice care still represents a minority of US deaths. In some cases, it may not be clear that a prognosis is 6 months or less, or the patient or family may not recognize or be prepared to accept that the patient has such a time-limited terminal prognosis. Goals of care may not be clearly defined because the discussions necessary for informed consent have not occurred. There may be sufficient clinical uncertainty about the prognosis that disease-modifying interventions such as chemotherapy, radiation therapy, blood transfusions, or intensive hospitalization are being appropriately elected. Some deaths are the result of rapid, unexpected decline, and cannot be anticipated.

Palliative Care Consultation

Palliative care consultation, in contrast to hospice care, is available to any patient with advanced disease, irrespective of short-term prognosis, and is offered concurrently with other physician, supportive, and consultative services. There are no interventions that are automatically precluded. Patients may elect, for example, to continue chemotherapy, dialysis, ICU admission, surgeries, or blood transfusion. Unlike in hospice, disease-modifying medications such as hematopoietic growth factors, enoxaparin, and parenteral antibiotics may be elected. Care by multiple consultants in multiple disciplines may continue.

Services are provided in 3 important areas. Patients may have moderate or severe symptoms that are uncontrolled. The knowledge gained through the hospice experience of the past several decades and shared by palliative care teams and hospice teams assures that patients will benefit from an interdisciplinary expertise in symptom control. Secondly, the palliative care team is able to initiate and guide complex discussions to help patients and families make decisions regarding appropriate and changing goals of care. The interdisciplinary consultation team (often a physician, nurse, social worker, and chaplain) can offer guidance and support to families and professionals in considering issues to ensure informed consent, including clarification of hopes of the patient and family and clarification of medically achievable outcomes. Election of a comfort-only goal is not presumed in guiding such conversations. Consultation can be a process that extends over months and multiple hospitalizations, the team continuing to work with families as the benefits and burdens of treatment change. Some programs provide outpatient follow-up. Finally, the consultation team can assist in discharge planning, which may result in home health agency referral, nursing home placement, or, if consistent with patient/family goals, referral to hospice programs. Although a number of patients receiving palliative care consultation services will ultimately enroll in hospice programs, hospice referral rates are not the primary outcome measure of team success; excellent symptom control and informed decision-making, however, are.

MEDICARE HOSPICE PROGRAM

Case Presentation: Mrs. Brendan

Mrs. Brendan, a 72-year-old woman, is being considered for hospice care. Two years ago, she was diagnosed with colon cancer and underwent surgery and chemotherapy. She appeared to be tumor free until 6 months ago, when she reported bone pain and a cough. Evaluation revealed recurrent colon cancer, metastatic to her bones, lungs, and liver. She has lost 11.3 kg (25 lb) in the past 4 months and has had nagging abdominal discomfort. She is mildly dyspneic and experiences moderate pain in the ribs and thighs, which she rates as 6/10 on an analogue scale. She takes ibuprofen as needed. She previously lived alone but now lives with her sister for help and companionship. She is increasingly dependent for help with activities of daily living.

Medicare Hospice Benefit

Required components of care. In 1983, Congress passed the Medicare hospice benefit, which established a payment model for hospice care and defined required components of care. Roles for the various members of the interdisciplinary team are identified in Figure 2. At the time of admission, a hospice plan of care is generated and approved by the attending physician and hospice medical director. Such a plan includes an overall assessment and recommendations for pain/symptom control (including medications), durable equipment needs, and hospice staffing. Staff visits are typically made to the place of residence, according to clinical need. Nursing visits generally occur on a weekly or biweekly basis, although daily visits can occur if the clinical situation warrants them. Nursing staff is always available to families; trained hospice personnel staff a 24-hour triage telephone. Visits by social workers and chaplains occur on a regular or an as-needed basis; hospice bereavement services are provided to the family for 15 months after a patient’s death. In addition to the Medicare program, Medicaid and many private insurance companies also offer hospice benefits. Moreover, many hospice programs make provisions to provide care to those without the means to pay.
The Medicare benefit was designed to support home care, and most care is rendered in the patient’s home. Care may also be provided in nursing homes, or, under qualifying conditions, in dedicated palliative care or hospice inpatient units. Indications for hospital care include the need for active titration of medications requiring rapid adjustments (most commonly in cases of severe pain, intractable nausea/vomiting, or marked agitation) and active dying in a family uncomfortable with death in the home setting. For patients requiring hospitalization, most hospices use contracted beds on a general medical floor. However, some hospices enjoy the benefit of dedicated in-patient hospice/palliative care units, in which a small number of beds exist in a distinct area of a hospital, and a dedicated staff trained and oriented toward comfort care attends the patient and family. For patients being cared for at home, respite care, limited to 5 days at a time, is available if the family requires relief from the burden of caring for the patient, whether that relief is to allow for travel away from the home or simple relief of the demands of caring for the patient.

Financial responsibility. The hospice program assumes financial responsibility for all medications related to the primary hospice diagnosis, for durable medical equipment (eg, hospital beds, commodes, wheelchairs), and for the participation of staff as previously outlined. If the patient requires more than periodic visits, the family is assisted in identifying caregivers paid by the family. If nursing home care is necessary, the hospice social worker assists in identifying appropriate sites; nursing home costs are borne by the family or by other government programs. Because Medicare patients can participate in only a single Medicare program at a time, patients must surrender conventional Medicare benefits when electing hospice care. However, when a hospice patient requires services for a medical condition not directly related to the hospice diagnosis (eg, a nonpathologic hip fracture or treatment of a concomitant thyroid condition), the patient continues to access conventional Medicare benefits while remaining in hospice. Such benefits could include hospitalization, surgery, or extensive diagnostic testing. Decisions regarding the extent of the evaluation and treatment should be tempered by the rule of proportionality (see Ethical Issues in End-of-Life Care, below).

Role of the family. The unit of care in the hospice model is not the patient but the family. At initial enrollment, there may be a very compelling need to gain control over a myriad of symptoms, and major attention is appropriately addressed to the patient. However, a patient’s decline and death is also the loss of a spouse, a child, a parent, a friend. As the patient progresses through terminal decline, his or her comfort needs often become increasingly straightforward. At the same time, however, the family’s need for both education regarding the process they are witnessing and emotional support becomes greater. A physician acting independently could provide good symptom control; excellent care of the patient and family, however, requires a team
of caregivers. Because of the interdisciplinary team of workers included in the program and its financing mechanism, the Medicare hospice program is among the best-supported programs in the United States.

### Medical Criteria for Admission to Hospice

The standard for admission to a Medicare hospice program is fairly straightforward: in the opinion of 2 physicians (usually, the referring physician and the hospice medical director), the patient is likely to die within the next 6 months, given the hospice diagnosis and comorbidities and assuming those conditions follow their usual course.\(^\text{13}\) This criterion does not include a mandate for special testing or specialist consultation but relies on the clinical judgment of the physicians. The difficulty in prognosticating death is well recognized, especially for diagnoses not involving cancer.\(^\text{14}\) Yet, the challenge of identifying those patients likely to die within the next 6 months is significantly easier than shorter-term prognostication. An often-used gauge is the question, “Would I be surprised if this patient died within the next 6 months?” If the answer is no, then the patient likely satisfies the prognostic criterion for hospice care.

The current hospice recertification process acknowledges prognostic uncertainty and creates a mechanism for thoughtful review. All patients are initially admitted for a 3-month benefit period. At regular intervals (3 months after initial enrollment, 6 months after enrollment, and then every 2 months, indefinitely), a patient must be recertified by the hospice medical director or the referring physician as meeting the 6-month prognosis criterion (ie, from the time of recertification). Patients do not need to die within 6 months of entry into a hospice program, but it is expected that patients will perceptively decline over each benefit period. When patients are discharged from a hospice program, either because of clinical improvement or clinical stability, the hospice program assists in establishing appropriate follow-up care. Moreover, patients may elect to return to active disease-modifying treatment after enrollment in a hospice program; such patients leave the hospice benefit and return to their usual model of care. There is no penalty, and such patients are welcomed back into hospice care should they again elect the goal of hospice care.

Although prognostication cannot be precise, certain diseases tend to follow certain patterns of decline. Cancer patients usually demonstrate a slow decline until the appearance of metastatic disease that is unresponsive to intervention; at this point, a much more rapid decline can be anticipated (Figure 3). Patients with chronic heart and lung disease, by contrast, tend to manifest a slow decline over time, punctuated by crises of decompensation and intensive hospitalizations (Figure 4). Although occurring against a background of progressive decline, death can still seem sudden and unexpected. Demented and frail patients tend to follow a course of inexorable but slow decline, ultimately dying of complications of infection and malnutrition (Figure 5).

In 1996, the Medicare Guidelines for Hospice Appropriateness were published.\(^\text{15}\) Based on outcomes-based research available at the time, the guidelines covered clinical situations consistent with death within 6 months. In general, these situations, combined with patient decline, are markers of a limited prognosis. In patients with a chronic, progressive primary diagnosis, factors such as weight loss, stage III or IV decubitus...
ulcers, aspiration, deep infections (eg, pyelonephritis, pneumonia, sepsis), and fever after antibiotic administration are all markers of significant decline likely consistent with a limited prognosis.

Criteria for a limited prognosis by specific organ system generally include end-stage symptoms. Patients with cardiac or pulmonary disease who require significant use of oxygen and have progressive conversational dyspnea or marked dyspnea on exertion, patients requiring a series of closely spaced hospitalizations because of decompensation of major organ systems, and patients foregoing further interventions (eg, patients with renal disease declining further dialysis, patients with cancer declining further chemotherapy) are likely to be hospice appropriate. Adult failure to thrive, a new diagnostic criterion added in 2000, applies when a patient loses more than 10% of body weight over 6 months despite nutritional interventions. The category of “debility unspecified” is designed for patients not meeting specific organ system criteria but declining sufficiently that 2 physicians certify a likely prognosis of 6 months or fewer of life.

In general, hospice-appropriate patients experience limitations in performance of a progressive nature. A commonly used rating scale is based on the Karnofsky Performance Scale, which was developed in the 1940s for use in determining likely survivability after chemotherapy. The Palliative Performance Scale (PPS) represents an expansion of the Karnofsky tool and includes parameters of ambulation, ability to perform work, independence in performing activities of daily living, nutritional intake, and cognitive ability (Table 1). A PPS of 50% or less corresponds to a patient no longer able to live independently. Such a patient may be living at home with supervision or may be in a nursing home (or be a candidate for such care). The addition of progressive medical conditions for which there are no major disease-modifying interventions either available or elected by the patient/family will define the patient as hospice appropriate.

Follow-up Discussion of the Case Patient

Mrs. Brendan has widely metastatic colon cancer. Her performance status is declining, as indicated by the change in her living arrangements and her significant weight loss. A realistic and respectful dialogue on her prognosis and future course, including discussion of her personal goals for care, needs to take place now, if such a discussion has not occurred in the past. Likely benefits of aggressive disease-modifying or life-prolonging treatment and of palliative/comfort care should be reviewed. If Mrs. Brendan has identified an agent for healthcare decisions, the agent should be present to hear and participate in the goals conference. Mrs. Brendan clearly qualifies for hospice care, given the extent of her disease, her declining performance status, and her significant weight loss. She is likely to die within the next 6 months, irrespective of interventions.

ETHICAL ISSUES IN END-OF-LIFE CARE

Numerous issues in the domain of biomedical ethics have special relevance in the care of patients toward the end of their lives. Especially relevant to the purposes of this discussion are the rule of proportionality; the principle of intended and unintended consequences, or double effect; and advance directives.
Rule of Proportionality

The rule of proportionality holds that the benefits of any given intervention should clearly outweigh the burdens of such an intervention. For example, in most patients with intestinal obstruction, the treatment includes gastric decompression and often preparation for surgery. The likelihood of successful recovery is sufficiently great as to counterbalance the risks of anesthetic or surgical accident, infection, hemorrhage, or complications during postoperative recovery. In contrast, in a woman with abdominally metastatic ovarian cancer and multiple obstructive sites, surgery will not lead to prolonged relief of the primary problem; a more appropriate intervention may be decompression with placement of a nasogastric tube if vomiting is marked, use of anticholinergic agents and opioids to control pain and diminish peristalsis, and supportive preparation for impending decline. These scenarios illustrate the importance of decision-making based on proportional benefit, especially in decision-making with patients with advanced progressive disease.

Death as a value or endpoint requires special consideration. The benefit of continued life may be considered so pre-eminent that all interventions to sustain life would be justified, because the burden of death is too great. However, in another situation, the values of the patient and family may be such that continued life does not carry this absolute value, and the relief of pain and suffering become the greater benefit. In the latter situation—and from the perspective of proportionality—allowing the dying process to proceed is morally acceptable.

Principle of Intended and Unintended Consequences

The principle of intended and unintended consequences, also called the double effect, recognizes that an action may have several outcomes. The most common medical application of this principle is in the context of opioid administration to a patient with respiratory insufficiency. If the desired primary benefit is the relief of breathlessness, but, in obtaining such relief, respirations are depressed sufficiently to contribute to death, the principle of the double effect holds that administration of the opioids is a justified and defensible act. The primary goal was comfort, not the death of the patient. (It should also be noted that the cause of death in such a situation is primarily the respiratory failure of the underlying disease process.) Thoughtful titration of medications to an endpoint of symptom control assures appropriate administration. If, on the other hand, a knowingly lethal dose of opioids is prescribed, the primary intent is no longer symptom relief but death. The latter usage of medication would be prohibited under the principle of double effect. This principle is invaluable in sorting through the ethical conflicts in prescribing for comfort at the end of life.

Advance Directives

Advance directives are written or spoken instructions on how a patient wishes to be treated in the future. Such instructions are relevant whether the patient is able to speak for themselves or not. If the patient is still decisional, the directives represent a summary of thoughts at the time they were written, and can serve as a starting point to guide further discussion. If the patient is not decisional, the directives serve as the patient’s voice.

There are 2 parts to an advance directive. The first is the identification of an agent for healthcare decision-making. The agency is activated when the patient is no longer decisionally capable. The most important function of identifying an agent and defining advance directives is the discussion that is thereby engendered. Without the pressure of crisis, and while the patient is still decisional, properly conducted advance directive discussions can be invaluable in allowing the patient to consider what is important in terms of goals and values. With the help of knowledgeable professional caregivers, including the physician and other staff, guidelines for future interventions can be discussed and directed. In the context of care toward the end of life, advance directives may address do not resuscitate (DNR) status and utilization of other life support interventions such as dialysis, feeding tubes, transfer to hospital, care in an ICU, or surgery. Such directives may also address the use of pressors, antibiotics, or insulin.

The least effective time to generate advance directives is in the crisis situation of impending major organ failure. At a minimum, all patients with advanced chronic disease or patients entering situations in which there is a significant risk of profound injury or decline (eg, major surgery, admission to the ICU, following a major stroke, prior to major cardiac procedures) should be afforded the opportunity to discuss and define their wishes in the future. Such discussion can then guide decision-making with the agent and family when the patient can no longer participate. If a patient has expressed wishes regarding care but has not documented these wishes in writing, such conversations still represent advance directives and should be used as guidelines in subsequent decision-making.

Most states have surrogate acts in place identifying agents for health care decision-making in the event that a person has not identified an agent or the agent is unwilling to serve in this capacity. In Illinois, for
example, the order of decision makers follows the outline of Table 2.¹⁹ States do not want to become involved in agency issues, except when there is no other option.

CONCLUSION

The past 40 years have seen the emergence of a systematic approach to the palliative care of the patient with advanced progressive disease. Formalized in the Medicare hospice benefit established in 1983, and now expanding though the development of palliative care consultation services, these excellent models of interdisciplinary palliative care are now widespread in the United States. Although prognosticating death is difficult, there are guidelines that can help in identifying those patients with progressive disease and an increasingly limited life expectancy, in whom the burdens of disease-modifying treatments increasingly do not outweigh the benefits of such treatments. For such patients, shifting toward a primary goal of care emphasizing comfort becomes appropriate.

Part 2 of this series will consider the management of specific symptoms, including pain.

REFERENCES


Table 2. Order of Surrogate Agents When None are Previously Identified (Illinois Statute)

| (1) | The patient’s guardian of the person (if previously appointed guardian exists) |
| (2) | The patient’s spouse |
| (3) | Any adult son or daughter of the patient (if multiple, by majority if consensus cannot be reached) |
| (4) | Either parent of the patient |
| (5) | Any adult brother or sister of the patient (if multiple, by majority if consensus cannot be reached) |
| (6) | Any adult grandchild of the patient (if multiple, by majority if consensus cannot be reached) |
| (7) | A close friend of the patient |
| (8) | The patient’s guardian of the estate (durable power for property) |

